Title: Kidney age, not kidney disease

Introduction (100 words max)

While a variety of conditions and syndromes may affect the kidneys over either chronic or acute time frames, the term "chronic kidney disease" (CKD) is used to describe a decrease in the filtration ability of the glomerular capillaries in the kidney {REFs}. Conventionally, all people with an estimated glomerular filtration rate (eGFR) less than 60 <units> are considered to have chronic kidney disease, along with those who have an eGFR between 60 and 90 and other signs such as proteinuria. This definition encompasses a wide range of kidney health states from sub-clinical, asymptomatic disease to end stage renal disease requiring transplant or dialysis to support life. In the UK, general medical practitioners are incentivized to enter patients with CKD on a register.

What constitutes a disease?

The most prevalent states of CKD in healthcare systems are typically the asymptomatic states conventionally termed CKD stage X {REFs} and in the population, those termed CKD stage Y {REFs}. Should these asymptomatic states be considered disease? Attempts to construct formal definitions of disease have each been multifactorial, but all require either negative consequences or abnormality in some statistical sense (or both) {Smart}.

Later stages of kidney disease certainly fulfil criteria for disease: CKD stage 5 for example is a harmful dysfunction of the kidneys, and statistically rare. CKD stages 2 and 3 however are not "harmful" or "unfortunate" except in as much as they are associated with elevated risk of disease: in particular, cardiovascular disease {REF}. Whether stages 2 and 3 are statistically abnormal depends on the age of the individual: we return to this point below.

This paper draws on published findings from quantitative and qualitative studies of CKD and is illustrated with patient quotes from our own study of 45 patients' experiences published at http://www.healthtalk.org/peoples-experiences/long-term-conditions/kidney-health/topics .

Is the label 'chronic kidney disease' helpful to patients or clinicians? (about 400 words) Qualitative data from both clinicians [Crinson et al 2010; Simmonds et al 2016] and patients [Daker-White et al 2015] have demonstrated that communicating a diagnosis of 'CKD' to patients is uncomfortable and unsatisfactory for all concerned. As soon as the words 'chronic' or 'disease' are introduced within a consultation, primary care physicians face an uphill battle to retrieve the situation with reassurance [Blakeman et al 2012]. The word 'chronic' is often misinterpreted by patients as meaning serious, and 'kidney disease' can trigger thoughts of dialysis and transplant because people are usually unaware that earlier stages of kidney impairment exist before treatment becomes necessary.

> "I couldn't understand how I could be described as having chronic kidney disease when it had only just been discovered. 'Chronic' to me means – well maybe mistakenly – that I've had it for a long long time … they keep using this word 'chronic' and I think the word 'chronic makes it sound worse than what it is, to me anyhow" (Eric; aged 79) .

> "Well - it worries me a bit, a bit about it, you know, because same as I said, my family has got a history of diabetes. My brother, he was older- one of my older brothers – he had kidney problems when he was quite young. And then he had kidney failure completely and he had a transplant done and that worries me a little bit… with me; we're both exactly the same build and everything. He had bowel cancer and it seems to me everything he got, I get." (Bill; aged 71)

Clinicians may avoid using the term CKD with their patients or disclosing the diagnosis altogether. Daker-White et al [2015] found that 19 of 26 CKD patients interviewed in their study had been told something about their kidney function but only four had been explicitly given a diagnosis of CKD. A study of clinician views found a concern amongst GPs about possibly alarming patients by giving them a disease label when their kidney function was only mildly impaired [Simmonds et al 2016]. However, in our study and Daker-White's [2015], non-disclosure of a CKD diagnosis led to some patients finding out about it by accident, such as when consulting a different clinician to usual who assumed they already knew. Such accidental disclosure could lead to shock, anger and upset.

> I went for my normal routine check up to have blood tests and blood pressure and water and that. And my diabetic nurse came in with the nurse that was doing the test to send away to have the results come back and she asked me if I'd like to join this programme that you're running. And I asked her what it was about and she explained in my language that it was due to kidney problems. And I went into defensive mode. I said, "No, I've never had kidney problems. I haven't got kidney problems with diabetes. It's you know, I've been told everything was all right." And then she told me that I had a kidney problem that was being monitored regularly and I asked her, "How long have I had it? Can you tell me when it was diagnosed?" And she said in 1997, which was an absolute shock. [laughs] We had a short discussion because she had to go and see to other patients and she was under the impression I knew. But my daughter and I had been to the doctors when the results came through before, and I'd asked about kidneys and they'd always said, "No, they're fine." So this really was a bit of a… a shock. I laughed about it at first. I thought that it was a bit of a mix up. But now I understand there isn't but yet I haven't had it explained to me quite what it entails or what it's about. It's something I've got to go back and have a chat about. (Joan; aged 70)

Blakeman et al [2012] found GPs in their study felt a need to underplay CKD when discussing it with patients. Patient participants in Daker-White's and our study reported having their kidney function described by doctors in euphemisms such as '*borderline'*, '*under par'or 'leaking kidneys'*, rather than as a chronic disease. Some were told that their kidneys were functioning as if there was only one of them, not two.

> Anyway I had these blood tests and that's when… one doctor said… I had a little problem so I went back to the doctor that sent me for it anyway and he said my kidneys weren't functioning properly. So he said, "What we've got to do is keep an eye on them… and so every month you have blood tests to make sure that they're functioning." (Pat; aged 62)

> I had previously been told that I had about one and a quarter kidney function but that's, I know that's not a measurement, but that's how it was described to me as someone who had one and a quarter kidney, although it's both my kidneys that are damaged. (Jackie; aged 59)

Regardless of the terms used by professionals to describe early stage CKD to their patients, where it is disclosed it is accompanied by efforts at reassurance that it is nothing to worry

about [Blakeman et al 2012]. In our study, being told not to worry without an accompanying explanation or acknowledgement of patients' knowledge of other people with severe kidney failure, often failed to provide sufficient reassurance to patients. They were left wanting more information about what might have caused their kidney impairment, the severity of it and what the test results meant, was it reversible and how quickly might it decline to a level where treatment would be needed, what kind of symptoms they should look out for and whether they could do anything to prevent further decline.

> **Interviewer: So before this happened to you did you know that people could have these kinds of problems with their kidneys?**
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> Well I've heard of it, yeah. Cos the lady round the corner, she had kidney failure, she was about my age and she used to have to go up the hospital three days a week, yeah. Because if my kidneys go that's it, isn't it, I mean…it's the end of you really, isn't it, if your kidneys fail.
>
> **Interviewer: Did the doctor have any reassuring words for you?**
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> No. Well she just said to me what I said to you. She said, "Hundreds of people live on one kidney, you can live your life on one kidney and it shouldn't affect you", so that's all she's told me.
>
> **Interviewer: Mm is that not reassuring?**
>
> Not really. Not really. I want to know why they're failing, that's what I want to know. I mean I'm not a drinker, I don't drink, so whether it is the medication or whether old age. Well she hasn't explained, she just, as I say, she has just said that my kidneys aren't working as they should and I'm almost living on one kidney, but I wasn't to worry because hundreds of people live on one kidney. But then it starts alarm bells ringing doesn't it? Why are your kidneys failing; what have I done to make them fail? Is it my lifestyle, is it tablets? I mean it can't be drink because I don't drink; is it coffee? You don't know, do you?
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> **Interviewer: But you do all that worrying despite the fact that she said not to worry?**
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> Mm, you still worry of course you do, course you do. (Elizabeth; aged 74)

However, where an explanation was offered patients felt more reassured. Knowing that their kidneys were still functioning sufficiently to not cause them any problems, that they were being regularly monitored and that their test results were satisfactory or stable, were all sources of reassurance, as well as the trust they had in their doctor. Many GPs regard reduced but stable kidney function in elderly patients as a natural result of ageing, and often use this as the basis for the explanation and reassurance they give their patients [Blakeman et al 2015; Simmonds et al 2016]. Increasing age was the most common explanation for kidney impairment offered to our patient participants, and in most cases was successful in providing reassurance that they need not worry about it.

> But as far as an explanation of why the kidneys aren't working perfectly, she [the GP] did, most recently, tell me that kidney function decreases as you get older, and I accept that as being the case like everything else. You get older you lose your memory and things. (Eric; aged 79)

Is "normal" dependent on age?

An age-related interpretation is supported by observational data. Population-based studies consistently show that prevalence of CKD depends strongly on age {REF Zhang 2008}, increasing

approximately ten-fold between young adulthood and middle-age (for example, between ages 18-30 and ages 61-75 in the US Kidney Early Evaluation Program {REF Brown 2005 CHECK} and continuing to increase into old age (for example, more than doubling between ages 65-69 and ages 90-94 in a Canadian study {REF Garg 2004 CHECK}.

In the Third (US) National Health and Nutrition Survey (NHANES III), Coresh et al. plotted eGFR against age {REF Coresh 2003}. The median, and the 5th and 95th centiles declined continuously with age across participants from age 20 to age 90 years. The same authors later showed that this relationship had remained remarkably constant between the original National Health and Nutrition Survey (NHANES, 1988-1994) and NHANES III (1999-2000) {REF Coresh 2005}.

Kidney age, not kidney disease?

Motivated by these qualitative and quantitative observations, and discussion with our lay co-authors, we hypothesize that declining kidney function could better be communicated to patients in the language of "kidney age" rather than "chronic kidney disease". Similar terminology has been used previously to communicate current health or health risk to patients {REFs}. Spiegelhalter has previously reviewed concepts of "heart age", "brain age" and "lung age" that are based on risk of future disease {REF}. Groenewegen {REF}, in a review of proposed "heart age" and "vascular age" metrics, distinguished those based on multivariate prediction of future risk from those based on a specific, current indicator of vascular health such as carotid intima media thickness (CIMT). In the latter approach, the vascular age of an individual with a given CIMT value is the age at which the median CIMT in a healthy population is this value {REF}.

We re-plotted the graphs of Coresh et al., using data from the 20XX NHANES survey (Figure 1), reversing the axes to propose a mapping from current categories of CKD to age bands. CKD stage 3A for example could be communicated as "kidney age 72 to 77 years", and stage 3B as "kidney age 77 to 81 years". The term "chronic kidney disease" would be reserved for those with later stages: in particular, stage 5, or symptomatic stage 4.

Our hypothesis is that this approach would in many cases avoid unnecessary anxiety, while still signalling concern where appropriate. When age is approximately concordant with the reported "kidney age", we hope that patients will (as some already do) understand the decline as a natural ageing process. Conversely, when "kidney age" is in excess of age, there is potential for patients to form an understanding of the severity based on the size of the discrepancy. In either case we hypothesize that the language of "kidney age" will avoid misunderstandings that arise from the jargon of "chronic" kidney "disease".

In our analysis of previous studies, we have used data from a North American study for convenience; consideration should be given to whether kidney age should be defined separately in different populations: for example, in different ethnic groups.

N.B. According to the guidance there should be a section on how this issue is handled in other countries.

Next steps

Given a candidate definition of kidney age for a given country or ethnic group, further work is merited to test our hypotheses that this concept has advantages over existing terminology. In the first instance, interviews or focus groups with patients, and also health care providers, should investigate the face validity and acceptability of the "kidney age" concept, and also explore other alternatives ("function" and "dysfunction", for example). If results are encouraging then intervention studies, for example with questionnaire outcomes, could study the change in terminology as an intervention to improve patient-doctor communication in the first instance, and patient understanding as a consequence. Some hoped-for consequences might be demonstrable on a large scale: for example, an increase in awareness among the proportion of patients on registers (such as the UK chronic kidney disease register).

The required change in language would need to be widespread, ideally reaching clinical guidelines (and software) as well as information materials for the public and for patients, but it would be minor, in that it does not in principle require changes to practice, or to the content (as opposed to the language) of clinical guidelines. Potential advantages include: better understanding in those with impaired but age-appropriate kidney function; similarly, readier understanding in those with age-inappropriate kidney function; hence, greater readiness of family clinicians to discuss declining eGFR with both groups; avoidance of confusion or distress arising from the jargon term "chronic"; reservation of the "disease" for the stages of kidney dysfunction that are associated with direct harms – and for which treatment exists. Although these are consistent with the qualitative research findings discussed above, we list them as a potential, rather than proven, advantage, and hope for further development and testing of the kidney age concept in the near future.

References

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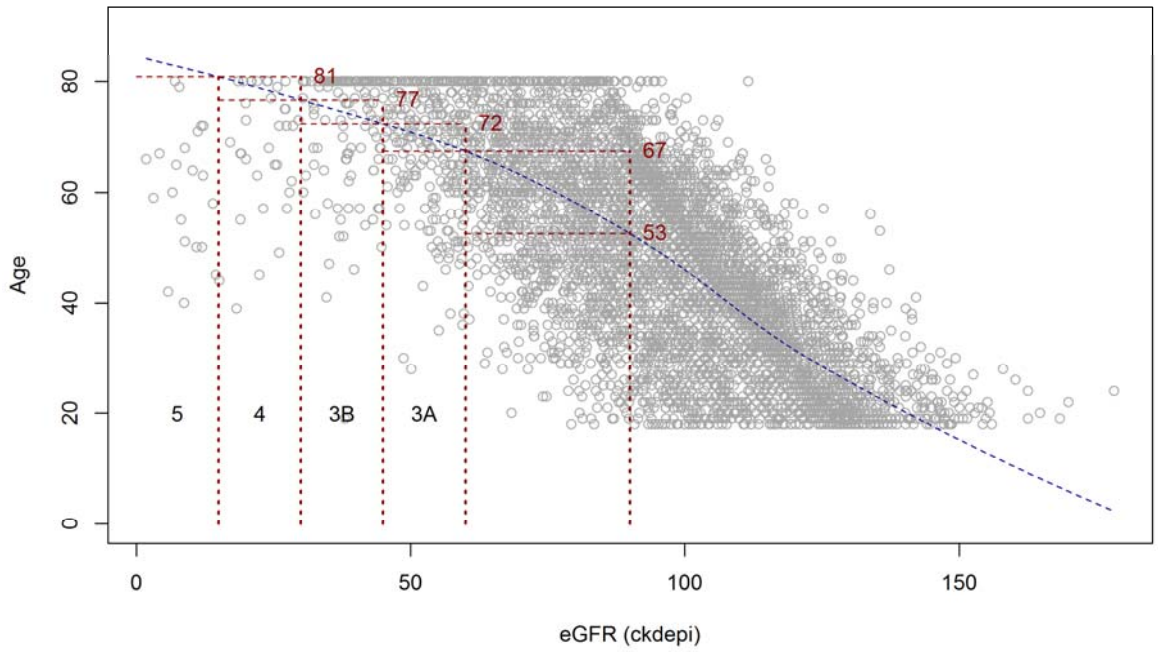

Figure 1. Mapping chronic kidney disease to age bands in observational data from the US National Health and Nutrition Examination Survey 20XX-XX.